Identification, classification and assessment of dyskinesia in children with cerebral palsy: a survey of clinicians

Original article

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Abstract

Aim: Investigate clinicians' knowledge, and barriers they perceive exist, relating to identification and measurement of dyskinesia (dystonia / choreoathetosis) in children with cerebral palsy (CP) and explore educational needs regarding improving identification and assessment of dyskinesia.

Method: Cross-sectional online survey of clinicians working with children with CP. Data analysis was descriptive with qualitative analysis of unstructured questions.

Results: 163 completed surveys from Australian clinicians were analysed. Respondents were allied health (n=140) followed by medical doctors (n =18) working mainly in tertiary hospitals and not for profit organisations. Hypertonia sub-types and movement disorders seen in children with CP appear to be identified by clinicians although limited knowledge about dyskinesia and access to training were reported as significant barriers to accurate identification. Despite knowledge of available measurement scales only a small percentage were used clinically and reported to be only somewhat useful or not useful at all. Barriers identified for use of scales included limited training opportunities and knowledge of scales and lack of confidence in their use.

Conclusion: A lack of confidence in identifying and measuring movement disorders in children with CP was reported by Australian clinicians. It was identified that a greater understanding of dyskinetic CP and the tools available to identify and measure it would be valuable in clinical practice. The results of this survey will inform the development of a 'Toolbox' to help identify, classify and measure dyskinetic CP and its impact on activity and participation using the framework of the International Classification of Functioning, Disability and Health.

Key Words:

Cerebral Palsy

Dyskinesia (dystonia / choreoathetosis)

Paediatrics

What is already known on this topic:

Dyskinetic CP is one of the most disabling forms of CP

Children with dyskinetic and mixed presentations of CP tend to respond differently to interventions compared to children with spasticity

Dystonia and/or choreoathetosis is generally under recognised, inconsistently reported on and poorly quantified

What this paper adds:

There is a broad range of knowledge regarding dyskinesia and specific movement disorders amongst medical and allied health personnel working with children with CP in Australia

Assessment of dyskinetic CP occurs largely in the hospital system for specific interventions such as ITB, DBS and medication trials

There is an identified lack of confidence in movement disorder identification and limited knowledge about available measurement tools

Introduction

Cerebral palsy (CP) is the most common cause of motor disability in children, with various international CP registers suggesting a prevalence of approximately 2-3 per 1000 live births[1,2]. CP can be classified by its distribution and predominant tone and motor type. Distribution refers to limb involvement, being unilateral or bilateral[1], tone abnormality being hypertonia or hypotonia[3] and motor type as spastic, dyskinetic (dystonic and/or choreo-athetoid), ataxic or mixed[1]. Classification of predominant motor type is important for guiding intervention for children with CP, although it is likely that the majority of children with CP present with components of spasticity, dystonia, choreoathetosis or ataxia[3,4].

Dyskinetic CP, one of the most disabling forms of CP[5], is a motor disorder characterized by changes in muscle tone and posture, with a varying element of involuntary movement[6]. In dyskinetic CP, dystonia and choreoathetosis are the two subgroups, however they are generally present simultaneously[6-8]. When dominance of dystonia and choreoathetosis is difficult to delineate, the term dyskinetic CP is used[9].

There appears to be some inconsistency in the identification and reporting of dyskinesia in children with CP between clinicians, the different international CP registers[5,10] and in the literature[1,3]. This may be due to clinical under recognition of dyskinetic CP[11] despite more recent increases in understanding and definitions. Neurological examination continues to inform the identification and differentiation of movement disorders[12]. The publication, in 2010, of the Hypertonicity Assessment Tool (HAT)[12] also enables reliable differentiation between paediatric hypertonia subtypes (dystonia, spasticity and rigidity) in the clinical setting. Accurate identification is imperative to guide both medical and therapy intervention, as children with dyskinetic CP can have different outcomes from the same treatments to those children with spasticity, more commonly seen and understood in CP[13,14]. Standardised and accurate measurement of dyskinetic CP is also important to determine intervention effectiveness, ensure practice is based on high quality evidence and guide future interventions.

Children with CP are generally seen by multiple teams of clinicians throughout their childhood. The majority of children in Australia are linked with a hospital team specialising in the care and medical management of children with CP. These teams usually comprise paediatric rehabilitation specialists and an allied health team of physiotherapists, occupational therapists, speech pathologists and specialist nurses. In addition, children frequently see specialists in neurology, orthopaedics, orthotics and psychology. Children are also linked with community therapy teams who provide ongoing, individualised, goal directed intervention. Community therapy teams in Australia are employed by not for profit or government organisations or are private practitioners. Many children also access therapy services via their school. It is important that all clinicians involved in the treatment of children with CP have a common understanding of prevalent movement disorders, their quantification and impact on function and intervention outcomes.

This study aimed to examine Australian clinician's knowledge around detection and differentiation of motor types, specifically dyskinesia, in children with CP, and their knowledge of the tools or methods commonly utilised for identification and measurement. Barriers clinicians perceive around accurate identification of dyskinesia and its measurement were also explored, in addition to perceived educational requirements to improve skills and expertise in this area. The outcomes from the survey will inform the development of a toolkit to improve knowledge in this area of clinical practice. The study formed part of a Knowledge Transfer Fellowship through the Centre of Research Excellence in Cerebral Palsy (CRE-CP) investigating the identification, classification and assessment of dyskinesia in children with CP. The CRE-CP is a five year project funded by the National Health and Medical Research Council in Australia that aims to improve the health and well-being of all people affected by CP and their families.

Methods

An online, anonymous, self-report survey was utilised. Hospital and community clinicians including medical doctors and allied health clinicians involved in the treatment of children with dyskinetic CP were targeted. Recruitment took place following ethics approval. Potential respondents were contacted via email from the membership of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM), CRE-CP and industry contacts in all Australian states, the latter being sub-sets of the AusACPDM membership. The 600 strong membership of the AusACPDM comprises physiotherapists, occupational therapists, speech pathologists, psychologists, special education and early childhood intervention teachers, paediatricians, rehabilitation specialists, orthopaedic surgeons, neurosurgeons, neurologists, and others interested in the field of CP and developmental medicine. Not all members work with children or patients with CP.

Survey Development

The custom designed survey, developed by the authors, formed the initial investigation into the clinical identification and assessment of dyskinesia in children with CP. Profession, caseload and workplace information including extent of clinical experience with children with CP was collected. Questions relating specifically to knowledge about dyskinesia in CP investigated whether clinicians identify and differentiated between different movement disorders, how this is achieved and any barriers they perceived regarding accurate identification of dyskinesia in children with CP.

A number of scales have been developed to measure dystonia and/or choreoathetosis severity. Only those scales that have been utilised with children with CP[15] were included. Knowledge about these scales was explored using questions about familiarity with the tools, their clinical utility and the purpose for which they were used. The scales, in order of publication include: the Burke-Fahn-Marsden Dystonia Rating Scale (BFMDRS)[16]; the Barry Albright Dystonia Scale (BADS)[17]; the Unified Dystonia Rating Scale (UDRS)[18]; the Movement Disorder Childhood Rating Scale (MD-CRS)[19] the Movement Disorder Childhood Rating Scale 0-3 (MD-CRS 0-3)[20] and the Dyskinesia Impairment Scale (DIS)[21]. The BFMDRS was developed for adults with primary dystonia and consists of a movement severity scale and a disability scale that assesses the impact of dystonia on select activities of daily living. The BADS, based on the BFMDRS, was developed specifically for people with secondary dystonia including CP and acquired brain injury and consists of a movement severity scale. The UDRS, also based on the BFMDRS and developed for primary dystonias, assesses dystonia severity and duration. The MD-CRS and MD-CRS(0-3) were developed specifically for children and assess the intensity of different movement disorders and their impact on function at targeted developmental levels. The DIS, developed specifically for people with dyskinetic CP, is the only scale to assess both dystonia and choreoathetosis on activity and at rest.
The final section of the survey explored respondents educational and clinical needs regarding dyskinesia identification and measurement, whether formal or informal training in this area had been undertaken and if further training or information around this topic were developed, what formats would be most useful for their clinical and/or research needs.

Survey data was captured and managed using REDCap (Research Electronic Data Capture) hosted at Murdoch Childrens Research Institute (https://redcap.mcri.edu.au). Data analysis consisted of descriptive statistics and frequency counts, as well as data driven qualitative analysis of the unstructured questions. The answers to these questions were fragmented, coded and categorised by identified descriptive words.

Results

A total of 163 Australian clinicians completed the survey, estimated to be 30% of the AusACPDM membership (Table 1). Clinicians comprised physiotherapists (58%), occupational therapists (24%) and medical doctors (13%) including rehabilitation / physical

medicine specialists, paediatricians, neurologists and orthopaedic surgeons, with smaller numbers of researchers, nurses, social workers and neuropsychologists. The majority were university qualified (98%) with 37% completing Masters level qualifications and 8% having doctoral qualifications. The majority of respondents (54%) had greater than ten years' experience working with children with CP. A further 29% had between five and ten years' experience, 13% one to four years' experience and the remainder less than one years' experience. Children with CP tended to comprise over fifty percent of the majority of caseloads, with only 12% of respondents having less than 10% of their caseload typically comprising children with CP.

Workplaces were largely tertiary hospitals (39%) and not for profit organisations (35%) with other respondents working in private practice, local hospitals, community health, government organisations, schools, universities and research facilities. Approximately 20% of respondents worked across two or more workplaces.

Ability to detect and differentiate movement disorders seen in children with CP

Over 92% of respondents indicated they do identify and differentiate the different motor types seen in the children with CP they manage (Table 2). Clinical judgement and observation was the most common method used to identify the presence or absence of the different movement disorders (91% of respondents), followed by use of assessment tools and classification systems (59%), multidisciplinary team assessment (56%) and video analysis (39%). Respondents who indicated they use a tool to help identify different movement disorders indicated they use the HAT (34%), the BADS (19%) and the Cerebral Palsy Description Form associated with the Australian Spasticity Assessment Scale (ASAS)[22] (11%) despite some of these tools not being designed for identification but rather measurement.

Spasticity and dystonia, the two most frequently seen motor types, were commonly identified by 99% and 93% of respondents. Ataxia, athetosis and chorea were less commonly identified (58%, 47% and 35% respectively). It is important to note that the survey specifically asked whether clinicians differentiated and described the differing motor types seen in the children with CP they treat and which motor types they commonly identified. These results do not necessarily reflect the accuracy of their recognition and identification. The main barriers identified for accurate identification (Table 2) included limited confidence (70%), limited knowledge of what the different motor types look like clinically (60%), lack of clinically applicable tools (79%) and limited training (64%) and access to training (64%) to help inform clinical decision making.

Knowledge about tools available to measure or quantify dyskinetic CP

The BADS was the most known scale, with 63% of respondents indicating they had knowledge of it. This was followed by the DIS (33%) and the BFMDRS (26%). All three of these scales were utilised overwhelmingly in tertiary hospitals (>80%) and largely used for assessment of medical interventions such as intrathecal baclofen therapy (ITB), deep brain stimulation (DBS) and medication trials. Survey responses indicated that few clinicians utilise specific measurement scales in routine therapy. Nearly a quarter of respondents had not heard of any of the scales (Table 3). Very few clinicians (<10%) had any knowledge of the UDRS or the MD-CRS and MD-CRS(0-3) with the majority only having heard of the scales and not used them in practice. Despite many respondents having some clinical knowledge of the various tools available, only a small percentage indicated they were very familiar with the tools and use them frequently (mean 14%) with the majority indicating they had used them once or twice or not at all.

The barriers, or potential barriers identified for use of the currently available tools to assess children with dyskinetic CP were limited training opportunities (51%), limited knowledge about the various tools (36%) and a lack of confidence in using them correctly (45%) (Table 4). Respondents also indicated they found the tools lacked clinical utility.

Educational and clinical needs regarding identification and measurement in Dyskinetic CP

Over half of survey respondents had not completed any training regarding the identification of movement disorders in children with dyskinetic CP (56%) (Table 5). Those that indicated they had completed some training had attended workshops at conferences, attended specialist dyskinesia training, completed formal CP training which included some identification of specific movement disorders and workplace in-services. The majority of respondents (>63%) indicated it would be extremely or very useful to both understand dyskinesia and the tools available to identify and measure it and that video of the differing movement disorders and how to assess them would be the most valuable training accompanied by written information, interactive workshops and web based training (Table 5).

Discussion

This online survey reported clinicians' current clinical practices and barriers they perceive exist regarding the identification and measurement of dyskinesia in children with CP and what educational initiatives would improve their understanding, identification and measurement of dyskinesia in CP. The majority of respondents were allied health personnel working in hospitals and not for profit organisations with graduate and post graduate qualifications and more than five years of clinical experience with CP.

It is promising that more than 95% of respondents indicated they do identify the different movement disorders they see in the children with CP, with spasticity and dystonia the most

commonly identified. This is occurring despite more than 40% of respondents indicating that lack of knowledge, poor access to training, limited confidence and a lack of clinically applicable tools make accurate identification a challenge (Table 2). Additionally 68% of respondents indicated that a greater understanding of dyskinetic CP would be extremely or very useful for their current clinical role, indicating there is a need for ongoing education in this area of practice for clinicians.

Currently there isn't any formalised training regarding dyskinesia identification and measurement in Australia. Only a third of survey respondents indicated they had attended some training around identification or for a specific measurement tool, largely in the form of conference workshops, workplace in-services and specialist courses. Despite the availability of various tools to identify and measure dystonia and/or choreoathetosis, there is a perception that they lack clinical utility and clinicians do not feel confident in their application and would find a greater understanding of these tools extremely or very beneficial clinically.

Limitations

The use of a voluntary, anonymous online survey means we cannot guarantee the results are truly representative of all clinicians working with children with CP, although representative samples of both years of clinical experience and workplaces indicate that responses are likely to be reflective of current knowledge. Selection bias is possible as clinician's known to be working with children with CP and affiliated with the AusACPDM or workplaces that specialise in the treatment of children with CP, were targeted, although this may also be viewed as a strength of the study. Another limitation is regards self-reported behaviours, which are frequently shown to overestimate actual performance[23]. This study focused only on tools that measure at the impairment level at a single point in time, which does not fully reflect the measurement of fluctuating conditions such as dyskinetic CP. It is appreciated that assessment across all the domains of the ICF is necessary and this survey reflects only one aspect of assessment of dyskinetic CP.

In conclusion, there is a broad range of knowledge regarding specific movement disorders, their identification and measurement amongst medial and allied health personal working with children with CP in Australia. Despite a range of readily available assessment tools, few are used clinically and those that are utilising them find them most useful as outcome measures for specific interventions such as ITB, DBS and medication trials. There appears to be a limited uptake of dyskinesia assessment as part of routine clinical care in children with CP. It is indicated that this is due to a lack of confidence in movement disorder identification and limited knowledge about the specific tools available to measure it. The development of a toolkit, providing detailed information regarding dyskinesia identification and assessment,

in conjunction with a targeted knowledge transfer strategy, will aim to address this gap in Australian clinician's knowledge and confidence.

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Table 1: Survey Demographic data

Factor	Categories	Respondents *n (%)*
Profession	Physiotherapist	95 (58.2)
	Occupational Therapist (OT)	39 (23.9)
	Rehab Specialist	11 (6.7)
	Rehab Specialist / Paediatrician	2 (1.2)
	Neurologist	1 (0.6)
	Paediatric Neurologist	3 (1.8)
	Neurologist / Paediatrician	1 (0.6)
	Orthopaedic Surgeon	3 (1.8)
	Speech Pathologist	4 (2.4)
	Nurse	2 (1.2)
	Social Worker	1 (0.6)
	Neuropsychologist	1 (0.6)
	Researcher (Physio or OT)	3
Educational level	Diploma	4 (2.4)
	Bachelor	85 (52.1)
	Masters	60 (36.8)
	Doctorate	13 (8)
	Other	1 (0.6)
Years of experience working with children with CP	< 1 year	5 (3.1)
	1 to 4 years	22 (13.5)
	5 to 10 years	48 (29.4)
	> 10 years	88 (54)
Proportion of caseload Children with CP	< 10%	20 (12.3)
	10-24%	25 (15.3)
	25-49%	28 (17.2)
	50-74%	42 (25.8)
	> 75%	48 (29.4)
Current workplace	Tertiary hospital	63 (38.7)
	Not for profit organisation	57 (35)
	Private practice	17 (10.4)
	Hospital	15 (9.2)
	Community health	14 (8.6)
	Government organisation	11 (6.7)
	University	4 (2.5)
	Schools)	8 (4.9)
	Research facility	7 (4.3)

 31 participants worked in more than one workplace

Table 2: Knowledge regarding Movement Disorders seen in children with CP

Factor	Categories	Respondents (%)
Differentiate / describe movement disorders	Yes	150 (92)
	No	7 (4.3)
	N/A	6 (3.7)
How identify Dyskinesia	Clinical judgement/observation	136 (91.2)
	MDT Assessment	83 (55.7)
	Video analysis	59 (39.6)
	Assessment tool/class system	88 (59.1)
	other	2 (1.3)
Assessment tools utilised (n=85 responses) ‡	HAT	56 (34.35)
	BADS / BFMDRS / DIS	31 (19)/ 12 (7.3)/ 10 (6)
	ASAS	19 (11.6)
	MAS / MTS	5 (3)/ 8 (4.9)
	Other	11 (6.7)
Movement disorders identified	Spasticity	148 (99.3)
	Dystonia	139 (93.3)
	Chorea	51 (34.2)
	Athetosis	69 (46.3)
	Ataxia	86 (57.7)
Barriers to accurate identification	Limited access to training	64 (40.8)
	Limited training availability	64 (40.8)
	Lack of time	40 (25.5)
	Limited applicability to caseload	23 (14.6)
	Limited knowledge – what different MD's look like	60 (38.2)
	N/A to current role	7 (4.5)
	Lack of clinically applicable tools	79 (50.3)
	Limited confidence to identify	70 (44.6)
	other	17 (10.8)

‡most respondents indicated more than 1 assessment tool; MDT= multidisciplinary team assessment; HAT=Hypertonicity Assessment Tool; BADS= Barry Albright Dystonia Scale; BFMDRS= Burke-Fahn-Marsden Dystonia Rating Scale; DIS=Dyskinesia Impairment Scale; ASAS=Australian Spasticity Assessment Scale; MAS=Modified Ashworth Scale; MTS=Modified Tardieu Scale; MD=movement disorders

Table 3: Knowledge about Tools available to measure or quantify dyskinetic CP

		BAD n (%)	BFMDRS	DIS	UDRS	MD-CRS & MD-CRS(0-3)
Knowledge of tool n=38 (23.3%) had no knowledge of any tools		103 (63.1)	42 (25.7)	53 (32.5)	16 (9.8)	13 (7.9) MD-CRS 8 (4.9) MD-CRS(0-3)
Familiarity	Very familiar, use frequently (Mean=18.3%)	25 (24.3%)	11 (26.2%)	6 (11.3%)	0	1 (7.7%)
	Somewhat familiar, used few times (Mean=48.5%)	57 (55.3%)	14 (33.3%)	28 (52.8%)	8 (50%)	3 (23.1%)
	Not familiar, heard of but don't use it (Mean=32.6%)	21 (20.4%)	17 (40.5%)	18 (34%)	8 (50%)	10 (77%)
Training	Training required for accurate use (Mean=89.9%)	96 (93.2%)	36 (85.7%)	48 (90.6%)	12 (75%)	12 (92.3%)
Type of Training required for accurate use	Read journal article	26 (25.2%)	12 28.6%	15 (28.3%)	4 (25%)	2 (15.4%)
	Clinical training by experienced clinicians	77 (74.8%)	31 (73.8%)	33 (62.3%)	7 (43.75%)	6 (46.2%)
	Manual	48 (46.6%)	15 (35.7%)	23 (43.4%)	5 (31.25%)	3 (23.1%)
	Course	31 (30.1%)	17 (40.5%)	26 (49.1%)	5 (31.25%)	5 (38.5%)
	Other (video's)	17 (16.5%)	5 (11.9%)	6 (11.3%)	3 (18.75%)	0
How clinically Useful is the tool	Extremely useful (Mean=12.8%)	1 (9.7%)	3 (7.1%)	11 (20.75%)	0	1 (7.7%)
	Somewhat useful (Mean=69.4%)	74 (71.8%)	20 (47.6%)	30 (56.6%)	7 (43.75%)	5 (38.5%)
	Not useful at all (Mean=17.8%)	8 (7.8%)	11 (26.2%)	6 (11.3%)	5 (31.25%)	5 (38.5%)
Main purpose for which tool is used	Routine therapy & Assessment (Mean = 15%)	22 (21.4%)	4 (9.5%)	7 (13.2%)	0	1 (7.7%)
	Routine MDT Assessment (Mean=24.7%)	32 (31.1%)	13 (31%)	10 (18.9%)	0	1 (7.7%)
	Med trials (Mean=24.7%)	31 (30.1%)	9 (21.4%)	13 (24.5%)	1 (6.25%)	2 (15.4%)
	DBS (Mean=29.1%)	27 (26.2%)	23 (54.8%)	12 (28.3%)	2 (12.5%)	2 (15.4%)
	ITB (Mean=27.75%)	36 (35%)	14 (33.3%)	11 (20.7%)	0	2 (15.4%)
	Research (Mean=20.3%)	21 (20.4%)	11 (26.2%)	9 (17%)	3 (18.75%)	2 (15.4%)
	Don't use it (Mean=30%)	22 (21.4%)	14 (33.3%)	16 (30.2%)	9 (56.3%)	7 (54%)

BADS=Barry Albright Dystonia Scale; BFMDRS= Burke-Fahn-Marsden Dystonia Rating Scale; DIS=Dyskinesia Impairment Scale; UDRS=Unified Dystonia Rating Scale; MD-CRS=Movement Disorder Childhood Rating Scale & MD-CRS(0-3)=Movement Disorder Childhood Rating Scale (0-3 years)

Table 4: Barriers (or potential barriers) to use of Tools available to measure or quantify dyskinetic CP

Factor	Categories	Respondents (%)
Barriers §	Limited training opportunities	83 (50.9)
	Lack of time to learn	42 (25.7)
	Lack of confidence using avail tools correctly/accurately	73 (44.7)
	Lack of time to complete assessments	60 (36.8)
	Limited applicability to total caseload	36 (22)
	Limited knowledge of the different tools that are available	60 (36.6)
	Limited knowledge which tools best suit different clinical presentations	68 (41.7)
	Tools not clinically meaningful or feasible	24 (14.7)
	My therapy team utilise tools for me as part of our full clinical assessment	15 (9.2)
	Other	11 (6.7)
	No response	12 (7.3)

§ Most respondents selected more than one option

Table 5: Educational and clinical needs regarding identification & measurement in Dyskinetic CP

Factor	Categories	Respondents (%)
Formal training in dyskinesia identification in children with CP	Yes	54 (33.1)
	No	91 (55.8)
Type of specific training:	DIS Course	16 (9.8)
	Bobath Courses	9 (5.5)
	Conference workshops	16 (9.8)
	HAT course	4 (2.4)
	Inservices/in-house training	23 (14.1)
Training on specific tool?	Yes	44 (27)
	No	101 (61.9)
Specific Tool training	DIS	20 (12.2)
	UDRS	2 (1.2)
	BAD	4 (2.4)
	BFMDRS	2 (1.2)
	HAT	6 (3.6)
	ASAS	3 (1.8)
	Conference workshops on tools	13 (7.9)
Would a greater understanding of dyskinetic CP be useful for your current clinical role?	Extremely useful	60 (36.8)
	Very useful	51 (31.2)
	Somewhat useful	27 (16.5)
	Not very useful	7 (4.3)
	Not useful at all	0
Would a greater understanding of the various tools available to identify and measure dyskinesia in children with CP be useful for your current clinical role?	Extremely useful	55 (33.7)
	Very useful	49 (30)
	Somewhat useful	29 (17.7)
	Not very useful	11 (6.7)
	Not useful at all	0
If a training package or "Toolkit" on identification & measurement for dyskinetic CP were developed, which format(s) would be of most benefit in your workplace:	Written information	67 (41.1)
	Video examples of MD's & how to Ax	125 (76.6)
	Video training (eg's of tools)	116 (71.1)
	Interactive workshops	83 (50.9)
	Webinars	87 (53.3)
	App – use in clinic to help identify & measure	76 (46.6)

DIS=Dyskinesia Impairment Scale; HAT=Hypertonicity Assessment Scale; UDRS=Unified Dystonia Rating Scale; BADS=Barry Albright Dystonia Scale; BFMDRS= Burke-Fahn-Marsden Dystonia Rating Scale; ASAS=Australian Hypertonicity Assessment Scale; MD=Movement Disorder; Ax=Assess